



End of Life Care December 2003

1: Adv Mind Body Med. 2003 Summer;19(2):24-7.

A model of hypnotic intervention for palliative care.

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The World Health Organization defines palliative care as "the active total care of patients whose disease is not responsive to curative treatment." One of the primary issues of palliative care for patients with advanced cancer is symptom control and quality-of-life issues. The purpose of the hypnotic model presented here is to improve the patient's total psychological, social, and spiritual well-being. There exists a need for a broad and inclusive model of mind-body interventions for palliative care. This is supported by the observation that symptoms related to psychological distress and existential concerns are even more prevalent than pain and other physical symptoms among those with life-limiting conditions. The following model integrates naturalistic, solution-oriented hypnosis within the framework of a situational 4-stage crisis matrix. The four stages of the matrix are: (1) The Initial Crisis, (2) Transition, (3) Acceptance, and (4) Preparation for Death. Hypnotic interventions are tailored to each stage in the crisis matrix.

Publication Types:

Review

Review, Tutorial

PMID: 14579808 [PubMed - indexed for MEDLINE]

2: Am J Crit Care. 2003 Nov;12(6):558-61.

Attending death as a human passage: core nursing principles for end-of-life care.

Benner P, Kerchner S, Corless IB, Davies B.

School of Nursing, Department of Social and Behavioral Sciences, University of California, San Francisco, Calif., USA.

PMID: 14619363 [PubMed - in process]

3: Am J Geriatr Cardiol. 2003 Jul-Aug;12(4):275-6.

When is deactivation of artificial pacing and AICD illegal, immoral, and unethical?

Silveira MJ.

Publication Types:
Case Reports
Letter

PMID: 14619876 [PubMed - indexed for MEDLINE]

4: Am J Nurs. 2003 Nov;103(11):48-51, 54-8; quiz 59.

End-of-life care of older adults.

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Publication Types:
Case Reports
Review
Review, Tutorial

PMID: 14625425 [PubMed - in process]

10: Arch Intern Med. 2003 Oct 27;163(19):2270-5.

Ethical challenges of partial do-not-resuscitate (DNR) orders: placing DNR orders in the context of a life-threatening conditions care plan.

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Do-not-resuscitate (DNR) orders are commonly found in treatment plans for patients near the end of life. Orders for partial resuscitation (eg, "do not intubate") have evolved from DNR orders. Although the ethics of DNR orders have been widely examined in the medical literature, little has been written about the ethics of partial resuscitation. This article explores the ethical implications of partial DNR orders and identifies the need to develop care plans addressing life-threatening conditions for patients with DNR orders.

PMID: 14581244 [PubMed - indexed for MEDLINE]

11: BMJ. 2003 Nov 22;327(7425):E256.

Oregon update.

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PMID: 14630782 [PubMed - indexed for MEDLINE]

12: BMJ. 2003 Nov 22;327(7425):1186.

Parliament to look again at issue of "assisted dying" for terminally ill patients.

Dyer O.

Publication Types:
News

PMID: 14630740 [PubMed - indexed for MEDLINE]

13: BMJ. 2003 Nov 8;327(7423):1068.

French doctor in euthanasia row faces murder charge.

Burgermeister J.

Publication Types:
News

PMID: 14604915 [PubMed - indexed for MEDLINE]

14: BMJ. 2003 Nov 1;327(7422):1011.

Adherence to advance directives in critical care decision making: vignette study.

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OBJECTIVE: To explore health professionals' decision making in a critical care

scenario when there is an advance directive. DESIGN: Qualitative study. SETTING: Scotland. PARTICIPANTS: Interviewees (n = 12) comprising general practitioners, hospital specialists, and nurses, and six focus groups (n = 34 participants) comprising general practitioners, geriatricians (consultants and specialist registrars), hospital nurses, and hospice nurses. RESULTS: When presented with an advance directive that applied to the same hypothetical scenario, health professionals came to divergent conclusions as to the "right thing to do." Arguments opposing treatment centred on the supremacy of autonomy as an ethical principle. Other arguments were that the decision to treat was consistent with the terms of the advance directive, or that, notwithstanding the advance directive, the patient's quality of life was sufficient to warrant treatment. CONCLUSION: Advance directives are open to widely varying interpretation. Some of this variability is related to the ambiguity of the directive's terminology whereas some is related to the willingness of health professionals to make subjective value judgments concerning quality of life.

PMID: 14593032 [PubMed - indexed for MEDLINE]

15: BMJ. 2003 Nov 1;327(7422):1048.

What is a good death? Grandmother's death was a good example.

Kittel M.

Publication Types:
Letter

PMID: 14593056 [PubMed - indexed for MEDLINE]

16: BMJ. 2003 Nov 1;327(7422):1048.

What is a good death? Good death may be possible in emergency departments.

Ganstal AI.

Publication Types:
Letter

PMID: 14593053 [PubMed - indexed for MEDLINE]

17: BMJ. 2003 Nov 1;327(7422):1049.

Comment on:
BMJ. 2003 Jul 26;327(7408):204-6; discussion 206-7.

Responding to unexpected events: patients have to be treated as individuals.

Iwanowska HM.

Publication Types:

Comment
Letter

PMID: 14593058 [PubMed - indexed for MEDLINE]

18: Br J Soc Work. 1998 Apr;28(2):161-75.

Euthanasia and assisted suicide: a survey of registered social workers in British Columbia.

Ogden RD, Young MG.

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This anonymous postal survey explores the attitudes and experiences concerning voluntary euthanasia (VE) and assisted suicide (AS) held by professionally registered members of the British Columbia Association of Social Workers. Social workers determine only a minor moral distinction between VE and AS and a large majority believe both acts should be legal, in certain circumstances (VE 75.9 per cent; AS 78.2 per cent). Approximately 80.0 per cent feel that social workers should be involved in social policy development concerning VE and AS, and, if such acts were to be legal, 70.0 per cent believe social workers should be involved in the decision making process with clients. Over 21.0 per cent of all social workers and nearly 40.0 per cent of social workers with medical employers have been consulted by a patient about VE or AS. Six respondents (1.1 per cent) reported assisting the death of a patient by VE. None had involvement in AS. Further research and education is required to better inform social work practice in this ethical area. Given the unique position of social workers in health care, they should, for the benefit of patients, families, and physicians, actively participate in the discussion concerning end of life decisions.

PMID: 14626254 [PubMed - indexed for MEDLINE]

19: Cancer. 2003 Dec 1;98(11):2502-10.

Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care.

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BACKGROUND AND METHODS: In part of a quality improvement program, the European Society of Medical Oncology (ESMO) surveyed its membership regarding their involvement in and attitudes toward the palliative care (PC) of patients with

advanced cancer. RESULTS: Of 895 members who responded, 82.5% were European and 12.1% were American. Sixty-nine percent of respondents reported that patients with advanced cancer constituted a major proportion of their practice; for 22% of respondents, patients with advanced cancer constituted most of their practice. Only a minority of respondents collaborated often with a PC care specialist (35%), a palliative home care service (38%), an in-patient hospice (26%), or a psychologist (33%). In response to questions regarding specific involvement in PC clinical tasks, respondents were involved more commonly in treating physical symptoms, such as pain (93%), fatigue (84%), and nausea/emesis (84%), than in managing psychological symptoms and end-of-life care issues, such as depression/anxiety (65%), existential distress (29%), or delirium (12%). Forty-three percent of respondents reported that they directly administered end-of-life care often, and 74% reported that they derived satisfaction from their involvement in end-of-life care. Overall, 88.4% of respondents endorsed the belief that medical oncologists should coordinate the end-of-life care for their patients, but a substantial minority (42%) felt that they were trained inadequately for this task. Positive attitudes toward PC were correlated highly with the degree of direct involvement in PC practice. Practitioners in private practice or teaching hospitals had substantially more positive attitudes regarding PC compared with physicians based in comprehensive cancer centers ($P < 0.05$). Although most of the responding medical oncologists expressed positive views regarding their involvement in the PC of patients with advanced cancer and dying patients, 15% of respondents had pervasively negative views. CONCLUSIONS: Most ESMO oncologists recognize the importance of PC and supportive care for patients with advanced cancer. Despite this, many are prepared inadequately for these tasks, and actual participation levels commonly are suboptimal. Copyright 2003 American Cancer Society.

PMID: 14635087 [PubMed - indexed for MEDLINE]

20: Cancer Invest. 2003;21(5):772-81.

Waiting for the platelet count to rise: negotiating care at the end of life.

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Oncologists play a crucial role in enabling patients at the end of life and their families to decide whether the burden of chemotherapy is worth the benefit. Using language that displays their concern for providing ongoing care and that does not mistakenly imply withholding of effective therapies can ease the transition off chemotherapy. Providing accurate, timely prognostic information; exploring patients' hopes, goals, and values; helping them resume meaningful activities; meeting their health care proxies and discussing the advance care plan with them can all enhance the relationship with patients at the end of life and ease fears of abandonment.

Publication Types:
Review
Review, Tutorial

Library Program Office
Office of Information
Veterans Health Administration

PMID: 14628435 [PubMed - indexed for MEDLINE]

21: Conn Med. 2003 Sep;67(8):497-503.

Congestive heart failure and the elderly.

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As patients age, congestive heart failure becomes an increasingly important problem and accounts for up to 20% of hospital admissions for patients over 65 years. With technological improvements in the treatment of coronary artery disease, improved survival after myocardial infarction, and better hypertension therapy, patients are living longer, thus the need for successful management of older patients with chronic heart failure. The elderly, especially minorities, tend to be under-represented in congestive heart failure trials. This article will focus on the care of the geriatric patient with congestive heart failure.

Publication Types:

Review

Review, Tutorial

PMID: 14587131 [PubMed - indexed for MEDLINE]

22: Crit Care Clin. 2003 Oct;19(4):789-810, viii.

End-of-life care in the critically ill geriatric population.

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As the geriatric population in the United States increases and better management of chronic diseases improves survival, more elderly will become critically ill and potentially require treatment in an intensive care unit (ICU). Dan Callahan has written, "... we will live longer lives, be better sustained by medical care, in return for which our deaths in old age are more likely to be drawn out and wild." Although no health care provider hopes for a drawn out and wild death for elderly patients, many geriatric persons will succumb to disease and die after having chosen and received ICU care. Recent data suggest that, on average, 11% of Medicare recipients spend more than 7 days in the ICU within 6 months before death.

PMID: 14601720 [PubMed - indexed for MEDLINE]

23: Crit Care Clin. 2003 Oct;19(4):713-27.

Chronic obstructive pulmonary disease in geriatric critical care.

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COPD is a progressive disorder that is punctuated in its later stages with acute exacerbations that present a risk for respiratory failure. COPD has a disproportionate impact on older patients. In the ICU, therapy is directed toward unloading fatigued respiratory muscles, treating airway infection, and prescribing bronchodilatory drugs. Most patients survive hospitalization in the ICU for an episode of respiratory failure. The severity of the underlying lung disease, however, underlies the poor outcomes of patients in terms of postdischarge survival and quality of life.

PMID: 14601716 [PubMed - indexed for MEDLINE]

24: Crit Care Clin. 2003 Oct;19(4):619-39, v-vi.

Culture, demographics, and critical care issues: an overview.

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The population dynamic and the immigration trends in the United States continue to challenge health care professionals who each day must serve an increasingly diverse population. Today's physicians must not only have a solid background in medical sciences but they must also have knowledge of how culture, race, and ethnicity impact how patients view and accept traditional Western practices. Whether doctors and patients are close in the "context spectrum" will often determine their ability to communicate beyond the spoken language. According to a report of the American Medical Association, by the year 2000, out of a total 812,770 physicians, only 2.5% were Black, 3.5% Hispanic, and 8.9% Asian. Only a fraction of a percent was American Native/Alaskan Native. Therefore, the majority of the physicians are Caucasian, and it could be assumed that they would likely be accustomed to high-context communication styles. The gross of the demographic changes and population increases in the United States during the past 10 years can be attributed to immigration from regions of the world where low-context communication styles are prevalent. Such differences between physicians and patients can create difficult, tense situations in an already charged atmosphere as can be that of a critical care unit.

PMID: 14601711 [PubMed - indexed for MEDLINE]

25: Crit Care Clin. 2003 Oct;19(4):811-25.

Controversial issues in critical care for the elderly: a perspective from

Canada.

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Age alone does not at all preclude the possibility of warranted, effective, and successful intensive care. From a medical perspective, the key issue is the reversibility or otherwise of an acute illness and where this illness sits in the trajectory of that individual's life and possible death. It makes no more sense to admit a 19-year-old let alone a 91-year-old to an intensive care unit if intensive care cannot provide what is needed. Of paramount importance in our consideration of critical care for the elderly is a determination and an understanding of the many needs--medical, emotional, social, spiritual, psychologic--that elderly people have. By exploring them with compassion and sensitivity, we can establish whether the goals of care include critical care and the associated technology, or whether alternative and more conservative approaches more closely reflect the values and preferences of an increasingly elderly population.

PMID: 14601721 [PubMed - indexed for MEDLINE]

26: EDTNA ERCA J. 2003 Jul-Sep;29(3):123-6.

Nursing terminally sick dialysis patients.

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The number of terminally sick patients (TSP) in haemodialysis (HD) is rising. The personnel that assist these patients wonder if they are sufficiently qualified to help and care for them and if TSP require treatment that is different to the other chronic dialysis patients. The reason for this study was to investigate if caring for TSP psychologically affected the infirmary personnel who looked after them during HD.

PMID: 14552084 [PubMed - indexed for MEDLINE]

29: Health Qual Life Outcomes. 2003 Nov 7;1(1):65. Epub 2003 Nov 07.

Life at the end of life: beliefs about individual life after death and "good death" models - a qualitative study.

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BACKGROUND: Different ideas of "good death" may influence the effectiveness of end-of-life care in patients with different ethos. This study aimed to identify the influence of believing in individual life after death on "good death" models. **METHODS:** Semi structured-interview to 8 persons, 4 believers and 4 non-believers in individual life after death from the general Italian population. Analysis of the transcribed text according to the method suggested by Mc Cracken. **RESULTS:** The analysis has shown a diverse and coherent conceptualization of death according to whether the subjects believe or not in individual life after death. Believers, for whom death marks the passage to a new dimension, prefer to be unaware of dying, while non-believers, for whom death is the end of the individual, prefer to be conscious until the very end of life. However some important aspects in common have been identified, i.e. having close people nearby, receiving assistance from experts, or the preference for a soft atmosphere around the dying person. **CONCLUSION:** There are aspects in common and aspects in contrast between believers and non-believers in individual life after death: while sharing many aspects of what a "good death" ought to be, they have opposite stands on being aware of dying. A plurality of models should be foreseen, accepting, in this case, their practical and theoretical implications.

PMID: 14613557 [PubMed - as supplied by publisher]

30: Int Urol Nephrol. 2002-2003;34(4):573-6.

The very elderly dialysis patient: indication and discontinuation of dialysis.

Schaefer K, von Herrath D, Faust J, Rohrich B.

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1. When the current available data in the literature is summarized it becomes evident that the majority of it supports the position that it is, at least for medical reasons, not advisable to exclude patients over the age of 80 years from chronic dialysis. 2. It is correct to say that the refusal of dialysis therapy for elderly dialysis patients would lead to a not insignificant cutting of costs, although elderly patients are not as 'expensive' as younger dialysis patients. 3. The decision to exclude patients over 80 from dialysis treatment is difficult, in our opinion, to support ethically. 4. The refusal of therapy by a dialysis patient--independent of his age--can only occur with his/her consent, as long as the patient is clearly conscious of the decision. 5. Should the patient no longer be in the condition to exercise his/her autonomy, and there is no AD, the Surrogate's Court must be consulted. 6. AD can be seen as helpful, since they not only make the decisions for physicians easier, but also because they can be seen as an act of care for family members. 7. Whenever dialysis therapy is discontinued the problematic nature of so-called essential care should be carefully considered, especially if no clear position has been taken in an AD.

PMID: 14577507 [PubMed - indexed for MEDLINE]

31: J Am Acad Psychiatry Law. 2002;30(4):581-4.

Physician-assisted suicide. Guarantees of privacy and liberty do not afford terminally ill patients the right to physician-assisted suicide.

Chamberlin JR.

Psychiatry and the Law Program, University of California, San Francisco, San Francisco, CA, USA.

Publication Types:
Legal Cases

PMID: 14606497 [PubMed - indexed for MEDLINE]

32: J Am Coll Surg. 2003 Nov;197(5):847-53; discussion 853-4.

The surgical intensivist as mediator of end-of-life issues in the care of critically ill patients.

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Publication Types:
Case Reports
Review
Review, Tutorial

PMID: 14585423 [PubMed - indexed for MEDLINE]

34: J Assoc Nurses AIDS Care. 2003 Sep-Oct;14(5):73-5.

Reflections on faith and healing.

Olsen NC.

PMID: 14571689 [PubMed - indexed for MEDLINE]

35: J Clin Nurs. 2003 Nov;12(6):860-72.

Home care with regard to definition, care recipients, content and outcome: systematic literature review.

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In spite of the fact that home care has grown considerably during the last few years and will continue to grow even more in the future, home care as a phenomenon and a concept is not clearly defined. The aim of this study was to review the empirical literature for the description of home care as a phenomenon and as a concept, especially with regard to who the care recipients are, what actions and assessments are performed and what effects are achieved for the care recipient in terms of functional health status and quality of life (QoL).

Twenty-six relevant studies meeting the inclusion criteria and requirements for methodological quality were identified. The phenomenon of home care is described through content, outcome and objectives. The content of home care involved a range of activities from actions preventing decreased functional abilities in old people to palliative care in advanced diseases. The outcome had two different underlying foci: (1). for the benefit of the patient based on the assumption that being cared at home increases their QoL, (2). in the interests of the society, to minimize hospital care by moving activities to the home of the patient. The objectives were found to be aiming at improving the QoL and/or maintaining independence, by means of actions and assessments, based on the patient's needs, undertaken to preserve and increase functional ability and make it possible for the person to remain at home. In conclusion, home care as a phenomenon was the care provided by professionals to people in their own homes with the ultimate goal of not only contributing to their life quality and functional health status, but also to replace hospital care with care in the home for societal reasons; home care covered a wide range of activities, from preventive visits to end-of-life care.

PMID: 14632979 [PubMed - in process]

36: J Crit Care. 2003 Sep;18(3):141-4.

Commentary: observational studies and their importance in improving end-of-life care in the intensive care unit.

Engelberg RA.

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Publication Types:
Comment

PMID: 14626210 [PubMed - in process]

37: J Law Med Ethics. 2003 Fall;31(3):365-76.

End-of-life care: forensic medicine v. palliative medicine.

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PMID: 14626545 [PubMed - in process]

38: J Neurosci Nurs. 2003 Oct;35(5):242-51.

Nursing care of patients with late-stage Parkinson's disease.

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Patients in the late stages of Parkinson's disease may be significantly disabled for many years, often because of their increasing inability to tolerate therapeutic doses of antiparkinson drugs. Their status and management have been overlooked in the literature. Few current healthcare professionals have cared for patients with Parkinson's disease in the prelevodopa era and do not understand how severe and protracted the illness can be without effective treatment. This article describes a practical approach to the nursing management of severely affected patients (i.e., Hoehn and Yahr Stage 4-5) who no longer derive consistent, therapeutic benefit from their drugs. Specific problems these patients face are adverse drug reactions such as postural hypotension, psychosis, and confusion, as well as difficulties with nutrition, elimination, mobility and falling, communication, sexuality, memory, and mood. Nursing interventions can help minimize the effect of these problems on the patient.

Publication Types:

Review

Review, Tutorial

PMID: 14593935 [PubMed - indexed for MEDLINE]

39: J Pain Palliat Care Pharmacother. 2003;17(2):71-82.

The Kansas Living Initiatives for End-of-Life Care.

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The Kansas Living Initiatives for End-of-Life Care (LIFE) project was formed in 1999 by over 70 Kansas organizations, agencies and associations to further the cause of dignified, comfortable and peaceful end of life in terminally ill patients. LIFE developed a module on end-of-life care that was added to the Kansas year 2000 Behavioral Risk Factor Surveillance system, convened meetings of partners including health professional licensing boards, reviewed state laws and regulations, and published a joint policy statement of the Kansas Boards of Healing Arts, Nursing and Pharmacy on the use of controlled substances for pain management. Activities of Project LIFE and outcomes are described.

PMID: 14649390 [PubMed - in process]

40: J Pain Palliat Care Pharmacother. 2003;17(1):39-45.

Symptom-related research from the agency for healthcare research and quality.

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Recent reports on research supported by the Agency for Healthcare Research and Quality are summarized. These reports relate to use of aspirin for cardioprotection by patients taking NSAIDs, end of life care for nursing home residents with advanced directives, Cancer Patients' Satisfaction With Primary Care Pain Management, the need for increased medical training about adverse drug events, and dorsal root entry zone lesioning for central neuropathic pain. The research summarized in this report was abstracted from the AHRQ Research Activities.

PMID: 14640339 [PubMed - indexed for MEDLINE]

41: J Pain Palliat Care Pharmacother. 2003;17(1):31-7.

The International Association for Hospice and Palliative Care: international activities and future initiatives.

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The International Association for Hospice and Palliative Care (IAHPC) is a global organization dedicated to the development and improvement of palliative care. The mission of IAHPC is to increase the availability and access to high quality hospice and palliative care for patients and families throughout the world. It does this by promoting communication, facilitating and providing education, and by becoming an information resource for patients, professionals, health care providers and policy makers around the world. This report describes activities of the IAHPC throughout the world and planned future initiatives.

PMID: 14640338 [PubMed - indexed for MEDLINE]

42: J Pain Palliat Care Pharmacother. 2002;16(1):61-79.

Palliative care: an international necessity.

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Palliative care is the care of patients whose disease is incurable and whose life expectancy is limited to weeks or months. This commentary describes the development of modern palliative care, some of the elements and underlying philosophical constructs of such care, and calls for expansion and improvement in end of life care throughout the world.

PMID: 14650450 [PubMed - in process]

43: J Pain Palliat Care Pharmacother. 2002;16(4):61-4.

Medications for patient comfort when weaning mechanical ventilation in palliative care.

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Indications for mechanical ventilation in end of life care and the place for weaning are discussed. Preferred medications to facilitate weaning are short acting benzodiazepines. The importance of the environment in which ventilatory support is provided is discussed as are ethical issues including patient wishes and those of a patient's proxy.

PMID: 14635826 [PubMed - in process]

44: J Pain Symptom Manage. 2003 Dec;26(6):1148-9.

An end-of-life care curriculum for nursing home staff. Improving nursing home care of the dying: a training manual for nursing home staff By Martha L. Henderson, Laura C. Hanson, and Kimberly S. Reynolds Published by Springer Publishing Company, New York, USA, 2003 216 pages, \$36.95 (softcover).

Budis JP.

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PMID: 14654267 [PubMed - in process]

46: J Palliat Care. 2003 Fall;19(3):168-75.

What is a good death? Minority and non-minority perspectives.

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While much attention has been directed at improving the quality of care at the end of life, few studies have examined what determines a good death in different individuals. We sought to identify common domains that characterize a good death in a diverse range of community-dwelling individuals, and to describe differences that might exist between minority and non-minority community-dwelling individuals' views. Using data from 13 focus groups, we identified 10 domains that characterize the quality of the death experience: 1) physical comfort, 2) burdens on family, 3) location and environment, 4) presence of others, 5) concerns regarding prolongation of life, 6) communication, 7) completion and emotional health, 8) spiritual care, 9) cultural concerns, 10) individualization. Differences in minority compared to non-minority views were apparent within the domains of spiritual concerns, cultural concerns, and individualization. The findings may help in efforts to encourage more culturally sensitive and humane end-of-life care for both minority and non-minority individuals.

PMID: 14606328 [PubMed - in process]

47: J Palliat Med. 2003 Oct;6(5):725-36.

Factors associated with the high prevalence of short hospice stays.

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This study's goal was to gain an understanding of the factors associated with hospice stays of 7 days or less (i.e., short hospice stays), and to test the hypothesis that independent of changes in sociodemographics, diagnoses, and site-of-care, the likelihood of a short hospice stay increased over time. We examined hospice stays for 46655 nursing home and 80507 non-nursing home patients admitted between October 1994 and September 1999 to 21 hospices across 7 states, and owned by 1 provider. Logistic regression was used to determine the factors significantly associated with a higher probability of a short stay. Compared to patients admitted in (fiscal year) 1995, and controlling for potential confounders, the probability of a short stay significantly increased in each year after 1995 in nursing homes, and in 1999 in non-nursing home settings. In (fiscal year) 1995, a nursing home resident admitted to hospice had a 26% probability (95% confidence interval [CI] 0.24, 0.28) of a less than 8-day stay and, in (fiscal year) 1999, the probability was 33% (95% CI 0.31, 0.34); a non-nursing home patient had a 32% probability in 1995 (95% CI 0.30, 0.34) and a 36% probability in 1999 (95% CI 0.34, 0.37). The probability of a short hospice stay was greater for patients with noncancer diagnoses, independent of year of hospice admission. In this paper we discuss the possible underlying reasons for the increased probability of short hospice stays and we speculate on what this increase may mean in terms of hospice's ability to provide high-quality end-of-life care.

PMID: 14622452 [PubMed - in process]

48: J Palliat Med. 2003 Oct;6(5):715-24.

Effectiveness of a home-based palliative care program for end-of-life.

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CONTEXT: Despite the widespread recognition of the need for new models of care to better serve patients at the end-of-life, little evidence exists documenting the effectiveness of these models. OBJECTIVE: To evaluate the effectiveness of a palliative program for end-of-life care. DESIGN: A comparison group study was conducted between March 1999 and August 2000 comparing subjects enrolled in a palliative care intervention to those receiving usual care. SETTING: Home Health Department at Kaiser Permanente, TriCentral Service Area. SUBJECTS: During the course of the 2-year study, 558 subjects were enrolled. A subgroup of 300 patients who had died during the course of the study was selected for analysis; 161 were enrolled in the Palliative Care Program and 139 in the comparison group. INTERVENTION: The Kaiser Permanente Palliative Care Project is a multidisciplinary care management approach for home-based end of life care and treatment. The program is designed to facilitate the transition from acute to palliative care during the last 12 months of life with the goal of improving quality of life through the provision of symptom control and pain relief, emotional and spiritual support, and patient education. MAIN OUTCOME MEASURES: Medical service use and satisfaction with services. RESULTS: Palliative care patients had increased satisfaction with services at 60 days after enrollment and significantly fewer emergency department visits, hospital days, skilled nursing facility days, and physician visits than those in the comparison group. Those enrolled in palliative care averaged a 45% decrease in costs as compared to usual care patients. CONCLUSION: Through integrating palliative care into curative care practices earlier in the disease trajectory, chronically ill patients nearing the end of life report improved satisfaction with care and demonstrate less acute care use resulting in lower costs of care. In addition, patients enrolled in the palliative care program were more likely to die at home than comparison group patients.

PMID: 14622451 [PubMed - in process]

49: J Palliat Med. 2003 Oct;6(5):782-5.

Ambulatory hospice training in family medicine residency.

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End-of-life care has become an important competency for primary care physicians, and yet many family physicians feel unprepared in the areas of hospice and/or palliative medicine. In preparation for designing an ambulatory geriatrics

rotation within a family medicine residency training program, a needs assessment revealed gaps in hospice training specific to the philosophy of hospice and the common settings in which it is practiced. A hospice-focused core curriculum unit was developed, using a community-based hospice experience and formal seminars. The resident's community-based experiences included home visits and nursing home contacts as part of a multispecialty hospice team. End-of-rotation resident assessments and rotations evaluations revealed enhanced resident understanding of hospice philosophy and venues, increased knowledge of the criteria for hospice admission and medical management of the dying patient and an increased intention to refer patients to a hospice program, although follow-up audits of referral patterns were inconclusive to date.

PMID: 14622464 [PubMed - in process]

50: J Palliat Med. 2003 Oct;6(5):809-20.

Introducing end-of-life care into the University of Cincinnati Internal Medicine Residency Program.

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PMID: 14622468 [PubMed - in process]

51: J Palliat Med. 2003 Oct;6(5):821-9.

Advancing End-of-Life Care: lessons learned from a statewide panel.

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The Florida Panel for the Study of End-of-Life Care was an innovative and effective approach to the formulation of end-of-life (EOL) policy recommendations that significantly influenced the legislative process and resulted in new EOL legislation. The lessons from this panel's experience are useful to other states considering legislative changes in their EOL policies. Key to the success of the EOL panel was its heterogeneous membership that allowed the collaboration of policy makers, clinicians, ethicists, citizens, and other stakeholders. Also, crucial to the success of the panel were the dimensions of the deliberative process embraced by the panel. This process supported an impressive level of mutual respect, trust, and openness among the panel members that, with only minor exceptions, allowed the members of the panel to rise above the parochial political battles that have often preempted serious debate on controversial EOL issues. The recommendations of the EOL panel led to new state laws on EOL care and improvements in public awareness, professional education, and clinical protocols for implementing patients' wishes. Another major but largely unforeseen consequence of the EOL panel was the development of

significant new working alliances among members and organizations. These alliances led to new projects on EOL care and have significantly improved communication and working relationships between organizations and individuals committed to improving EOL care.

PMID: 14622469 [PubMed - in process]

52: J Palliat Med. 2003 Oct;6(5):831-9.

Palliative care management: a Veterans Administration demonstration project.

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As part of a Veterans Health Administration (VA) commitment to improve end-of-life care the VA Greater Los Angeles Healthcare System (GLA) implemented Pathways of Caring, a 3-year demonstration project targeting patients with inoperable lung cancer and advanced heart failure and chronic lung disease. The program utilized case-finding for early identification of poor-prognosis patients, interdisciplinary palliative assessment, and intensive nurse care coordination to optimize symptom management, continuity and coordination of services across providers and care settings, and support for families. Program evaluation used patient and family surveys as well as reviews of medical records and administrative databases to assess processes and outcomes of care. Despite significant programmatic challenges including organizational instability and evaluation design issues, the program achieved measurable success including high rates of advance care planning, hospice enrollment, and death at home, and low end-of-life hospital and Intensive Care Unit (ICU) use. As a result of its success, the program will be expanded and its care model extended institution-wide.

PMID: 14622470 [PubMed - in process]

53: J Palliat Med. 2003 Oct;6(5):841-50.

Completing a life: development of an interactive multimedia CD-ROM for patient and family education in end-of-life care.

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There are relatively few comprehensive and empowering educational tools to assist people with terminal illness in addressing important end-of-life issues. Identifying this scarcity, a design team of health and multimedia professionals created an interactive, educational CD-ROM entitled Completing a Life. The primary goal of the project was to provide rich content in a style that was easy to access, understand, and use. The interactive medium of the CD-ROM enabled a

large amount and wide array of material to be presented in manageable segments. These segments are connected by hyperlinks, providing self-guided control over the selection, pace, and order of material. The CD puts the learning experience in the hands of the learner. The format and design is also intended to generate a sense of empowerment, at a time and around issues often associated with a loss of control. Completing a Life covers a wide range of information for the user to choose from, spanning physical, emotional, family, and spiritual issues. A calm and comforting tone and welcoming environment enhances the users' ability to take in the information and make proactive decisions about his/her own well-being and care. The CD contains video narratives of individuals who tell their own stories of living with terminal illness. In addition to being a highly relevant means of conveying sensitive, health-related information, this collection of personal interviews may offer a form of "virtual support group" for the user. Finally, the interactive format allows stories and informational content to be linked in topic-specific ways that complement one another.

PMID: 14622471 [PubMed - in process]

54: J Palliat Med. 2003 Oct;6(5):699-705.

A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs.

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BACKGROUND: Current end-of-life hospital care can be of poor quality and high cost. High volume and/or specialist care, and standardized care with clinical practice guidelines, has improved outcomes and costs in other areas of cancer care. **METHODS:** The objective of this study was to measure the impact of the palliative care unit (PCU) on the cost of care. The PCU is a dedicated 11-bed inpatient (PCU) staffed by a high-volume specialist team using standardized care. We compared daily charges and costs of the days prior to PCU transfer to the stay in the PCU, for patients who died in the first 6 months after the PCU opened May 2000. We performed a case-control study by matching 38 PCU patients by diagnosis and age to contemporary patients who died outside the PCU cared for by other medical or surgical teams, to adjust for potential differences in the patients or goals of care. **RESULTS:** The unit admitted 237 patients from May to December 2000. Fifty-two percent had cancer followed by vascular events, immunodeficiency, or organ failure. For the 123 patients with both non-PCU and PCU days, daily charges and costs were reduced by 66% overall and 74% in "other" (medications, diagnostics, etc.) after transfer to the PCU ($p < 0.0001$ for all). Comparing the 38 contemporary control patients who died outside the PCU to similar patients who died in the PCU, daily charges were 59% lower (US dollars 5304 +/- 5850 to US dollars 2172 +/- 2250, $p = 0.005$), direct costs 56% lower (US dollars 1441 +/- 1438 to US dollars 632 +/- 690, $p = 0.004$), and total costs 57% lower (US dollars 2538 +/- 2918 to US dollars 1095 +/- 1153, $p = 0.009$). **CONCLUSIONS:** Appropriate standardized care of medically complex terminally ill patients in a high-volume, specialized unit may significantly lower cost. These results should be confirmed in a randomized study but such studies are difficult to perform.

PMID: 14622449 [PubMed - in process]

55: JAMA. 2003 Nov 12;290(18):2379-80.

A piece of my mind. Grams.

Dean C.

PMID: 14612460 [PubMed - indexed for MEDLINE]

56: JAMA. 2003 Oct 15;290(15):2056.

Comment on:

JAMA. 2003 Jul 2;290(1):98-104.

Complexities in prognostication in advanced cancer: "to help them live their lives the way they want to".

Markowitz AJ, McPhee SJ.

Publication Types:

Comment

PMID: 14559960 [PubMed - indexed for MEDLINE]

60: Mayo Clin Proc. 2003 Nov;78(11):1397-401.

Use of opioids in the treatment of severe pain in terminally ill patients--dying should not be painful.

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Pain is a common symptom at the end of life. The vast majority of pain can be readily managed if simple principles of practice are followed. Chronic pain requires continuous analgesia, and severe pain requires use of strong analgesics, most commonly the opioids. In addition to drugs administered continually, short-acting medications must be available for "breakthrough" pain. This article reviews the principles of pain management in terminally ill patients, using a case-based demonstration.

Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 14601699 [PubMed - indexed for MEDLINE]

61: N Engl J Med. 2003 Nov 13;349(20):1891-2.

Comment on:

N Engl J Med. 2003 Nov 13;349(20):1936-42.

Costs to society of family caregiving for patients with end-stage Alzheimer's disease.

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Publication Types:
Comment

PMID: 14614164 [PubMed - indexed for MEDLINE]

62: N Engl J Med. 2003 Nov 13;349(20):1936-42.

Comment in:

N Engl J Med. 2003 Nov 13;349(20):1891-2.

End-of-life care and the effects of bereavement on family caregivers of persons with dementia.

Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, Thompson L, Belle SH; Resources for Enhancing Alzheimer's Caregiver Health Investigators.

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BACKGROUND: Although family caregiving has been intensively studied in the past decade, little attention has been paid to the impact of end-of-life care on caregivers who are family members of persons with dementia or to the caregivers' responses to the death of the patient. **METHODS:** Using standardized assessment instruments and structured questions, we assessed the type and intensity of care provided by 217 family caregivers to persons with dementia during the year before the patient's death and assessed the caregivers' responses to the death. **RESULTS:** Half the caregivers reported spending at least 46 hours per week assisting patients with activities of daily living and instrumental activities of daily living. More than half the caregivers reported that they felt they were "on duty" 24 hours a day, that the patient had frequent pain, and that they had had to end or reduce employment owing to the demands of caregiving. Caregivers exhibited high levels of depressive symptoms while providing care to the relative with dementia, but they showed remarkable resilience after the death. Within three months of the death, caregivers had clinically significant declines in the level of depressive symptoms, and within one year the levels of symptoms were substantially lower than levels reported while they were acting as caregivers. Seventy-two percent of caregivers reported that the death was a

relief to them, and more than 90 percent reported belief that it was a relief to the patient. CONCLUSIONS: End-of-life care for patients with dementia was extremely demanding of family caregivers. Intervention and support services were needed most before the patient's death. When death was preceded by a protracted and stressful period of caregiving, caregivers reported considerable relief at the death itself. Copyright 2003 Massachusetts Medical Society

Publication Types:

- Clinical Trial
- Multicenter Study
- Randomized Controlled Trial

PMID: 14614169 [PubMed - indexed for MEDLINE]

63: Nurse Educ. 2003 Nov-Dec;28(6):266-70.

The end-of-life nursing education consortium (ELNEC) experience.

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The End-of-Life Nursing Education Consortium (ELNEC) is a train-the-trainer educational program to help nursing faculty integrate care of the dying patient and the patient's family in the nursing curriculum. The authors describe the ELNEC experience, which prepares nurse educators to competently teach end-of-life care, and provides them with the necessary knowledge, skills, and resources to effectively integrate end-of-life content into existing nursing curricula.

PMID: 14624125 [PubMed - in process]

64: NY Times (Print). 2003 Nov 6;;A9.

French doctor expected to be charged in assisted suicide case.

Smith CS.

Publication Types:

- Newspaper Article

PMID: 14621705 [PubMed - indexed for MEDLINE]

65: NY Times (Print). 2003 Oct 26;;A18.

In feeding-tube case, many neurologists back courts.

McNeil DG.

Publication Types:
Newspaper Article

PMID: 14610772 [PubMed - indexed for MEDLINE]

66: NY Times (Print). 2003 Oct 16;;A14.

Feeding tube is removed in Florida right-to-die case: governor says he will try to stop death.

Goodnough A.

Publication Types:
Newspaper Article

PMID: 14610770 [PubMed - indexed for MEDLINE]

67: NY Times (Print). 2003 Jul 2;;A21.

Racial differences are found in use of feeding tubes.

McNeil DG.

Publication Types:
Newspaper Article

PMID: 14621710 [PubMed - indexed for MEDLINE]

68: ONS News. 2003 Oct;18(10):1, 4-6.

Models of palliative care: moving beyond hospice.

Rutledge DN.

Department of Nursing, California State University at Fullerton, USA.

PMID: 14608718 [PubMed - indexed for MEDLINE]

72: Public Aff Q. 2003 Apr;17(2):121-39.

The practice of a clinical ethics consultant.

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University of Washington School of Medicine, USA.

PMID: 14552294 [PubMed - indexed for MEDLINE]

75: Support Care Cancer. 2003 Nov 20 [Epub ahead of print].

Attitudes to terminal patients' unorthodox therapy: Finnish doctors' responses to a case scenario.

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We carried out a postal survey of a sample of Finnish doctors (n=1182) concerning their attitudes and ethical decisions in end-of-life care. A scenario was presented in which a patient with terminal cancer wished to obtain unorthodox treatment. Factors possibly influencing decision making such as general attitudes, life values and demographics were investigated. The response rate was 62%. The patient's plan to use unorthodox treatment was accepted by 54% of doctors. Gender or speciality did not influence the decision, but doctor's age was a significant factor (P=0.0005). Doctors aged 35-49 years were more accepting; younger and older ones less accepting. Doctors who had clinical experience in terminal care were more compliant to the patient's plan (P=0.034). A stepwise logistic regression analysis was used to create a model for explaining not accepting versus accepting the treatment with the background variables. Altogether eight independent significant variables were included in the final model of explaining a doctor's choice in the presented scenario. According to the model the patient's wish was more frequently accepted if the doctor was middle-aged, had clinical experience in terminal care, valued a high standard of living, considered terminal care satisfying, was less critical of health economics, considered advance directives helpful, had a high fear-of-death index score, and valued professional status less.

PMID: 14628213 [PubMed - as supplied by publisher]

76: Teach Learn Med. 2003 Fall;15(4):247-51.

Wit: using drama to teach first-year medical students about empathy and compassion.

Deloney LA, Graham CJ.

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BACKGROUND: Training in empathy and compassion can foster altruism in medical students. DESCRIPTION: To use the drama Wit in an experiential learning module for first-year medical students. Students and faculty received tickets to a Wit performance. Students heard a pre-play lecture on end-of-life care and attended a post-play discussion with the cast. Each attendee completed an evaluation survey for the Wit Educational Initiative, and site-specific responses were computed. Students reflected on their experience in an e-mail dialogue with clinical faculty. Students could also earn extra credit by completing a written assignment. EVALUATION: Attendance was excellent--99% of the class and 59% of

their preceptors. Most rated the performance as "excellent" or "very good" and reported they were moved emotionally. Reflecting on the performance, students admired the "science" of medicine but found the "art" of medicine lacking. CONCLUSION: When used effectively, theater can be used to promote attitude change.

PMID: 14612257 [PubMed - in process]

77: W V Med J. 2000 May-Jun;96(3):455-7.

Concerns and self-reported competencies in end-of-life care: a survey of physicians in WV.

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To assess concerns and self-reported competencies in end-of-life (EOL) care, we surveyed a random sample of West Virginia physicians and received 255 responses (33%). Those responding identified three major barriers to good EOL care: patient and family demands for all possible treatments, lack of physician education and inadequate financing. Most identified themselves as less than informed about EOL legislative and regulatory issues and were less than satisfied with their EOL symptom management skills. Most reported that their patients would want hospice care at the end of their lives, but indicated that a major reason for not referring a patient to hospice was patient and family denial of approaching death. Most respondents rated the overall quality of EOL care in West Virginia as fair to poor. We conclude that physician respondents recognize the need to improve their knowledge and skills in EOL care to improve the care of the dying in West Virginia.

PMID: 14619138 [PubMed - in process]